Report on the Governor's Commission on Lyme and Other Tick-Borne Illnesses

2001-2002

"SAFE AND HEALTHY LIVES IN SAFE AND HEALTHY COMMUNITIES"

THE RHODE ISLAND DEPARTMENT OF HEALTH
2003

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The Governor's 2001-2002 Commission on Lyme and Other Tick-Borne Diseases: Executive Summary

The Governor's Commission on Lyme and Other Tick-Borne diseases was formed in response to the prevalence of Lyme disease in Rhode Island and the damage this disease has caused Lyme sufferers, their families, and their communities. The Commission met between February 12, 2002, and April 17, 2002. Participants initially discussed several issues surrounding Lyme disease in Rhode Island, including the problem of public awareness of the disease, physician education, and the disparity between current medical literature regarding Lyme and patient experiences. The Commission members elected to discuss issues of prevention, education, diagnosis, and treatment, to review Connecticut policy, and to hear testimony from tick-borne disease experts and from the public. The Commission divided into two subcommittees, one subcommittee to concern itself with Prevention and Environmental Issues, and a second subcommittee to deal with the issues of Lyme Disease Treatment and Diagnosis. Each subcommittee met once. The Commission held a public hearing on April 8 and another on April 17. During these hearings, committee members heard testimony from tick-borne disease experts, including physicians, researchers, and advocates, who related their research on and experiences with Lyme disease. They also heard testimony from individuals who either suffered from Lyme disease or witnessed the suffering of a loved one. These numerous individuals related their experiences with physicians, with insurance companies, and with their difficulties obtaining a diagnosis and appropriate treatment.

The following list is a summary of the recommendations that were reviewed by the Commission:

- Educate the public about Lyme disease including the hazards of ticks, how to prevent tick bites, strategies for preventing Lyme disease, and symptoms of Lyme disease.
- Educate the public through schools, physicians' offices, emergency rooms, and childcare centers.
- Educate the public about Chronic Lyme disease.
- Educate physicians about Lyme disease, including such topics as understanding all the criteria that can be applied to diagnose Lyme disease, how to recognize all the possible symptoms and deviations from the common symptoms, and knowledge of the scope of potential treatments and their side effects.
- Educate physicians about Chronic Lyme disease.
- Investigate the possibility of having a Tick Coordinator for the State of RI.
- Survey the tick population throughout the entire state.
- Examine tick-reducing landscaping techniques.
- Examine the use of pesticides as they relate to Lyme disease.
- Ensure occupational protection for high-risk State employees and others in similar occupations.
- Investigate and employ strategies for deer control.
- Allow physician discretion in clinical diagnosis of Lyme disease. Allow diagnosis to be wider than outlined in the CDC guidelines.
- Allow physician discretion in treatment of Lyme disease, including the prescription of long-term antibiotics.
- Recognize Chronic Lyme disease as a problem in Rhode Island.
- Require insurers to extend coverage on Lyme treatment.
- Protect physicians who diagnose chronic Lyme disease from censure by medical review boards and insurers.

Summary Report: Governor Lincoln Almond's Commission on Lyme and Other Tick-Borne Illnesses - 2001 and 2002

Lyme disease is a growing problem in Rhode Island. After Connecticut, Rhode Island has the highest rate of reported Lyme infection, with an estimated 81.3 out of 100,000 people having been infected in 2002, and the rate is increasing. As the number of Lyme cases increases, so does public concern. Every year, Rhode Island newspapers from the *East Bay Newspapers* to the *Providence Journal* print lengthy articles on Lyme disease, including stories about families who have suffered greatly from the debilitating effects of Lyme. Likewise, physicians from New England and surrounding states have often described Lyme in Rhode Island as an "epidemic."

Over the years, Lyme has proved a financial drain on society. In 1993, Irwin Vanderhoof, an actuary at New York University's Stern School of Business, estimated that Lyme costs society $1 billion each year, a number that is likely higher today. However, even using this number, and assuming that Rhode Island experiences only approximately 3% of all Lyme cases, the state would still be experiencing a $30 million annual drain from Lyme. This number takes into account not only the costs of testing and treating Lyme, but also the cost of unnecessary and inappropriate treatment, the loss of productivity in the labor force, and the cost of legal fees.

Individuals and families have suffered the loss of not only their health from this disease, but also the loss of income from their own decreased productivity and financial drain from medical expenses not covered by insurance. These people suffer physically, emotionally, and financially, some to the point of desperation.

These are some of the issues that prompted the formation of Governor Lincoln Almond's Commission on Lyme and Other Tick-Borne Illnesses in 2001 and 2002. Herein, we shall look at the events that took place during that Commission and the suggestions and resolutions that emerged.

Prior to the commission, individual towns in Rhode Island had already begun discussing measures to counter the Lyme problem. In September of 2000, the Town of Westerly held a meeting to discuss the effects of Lyme and other tick-borne diseases (such as Babesiosis, Bartonella, Ehrlichia, or Rocky Mountain Spotted Fever) and possible resolutions. A summary of that meeting is summarized in Appendix B of this report.

Shortly after the Commission was formed, bills were introduced to the Rhode Island State Senate and House of Representative regarding insurance coverage for Lyme treatment. These bills, S 2703 and H7996, "An Act Relating to Health Insurance Coverage," requires all insurers and hospitals to guarantee coverage of 30 days of intravenous antibiotic therapy and 60 days of oral antibiotic therapy for all Lyme patients. Senators V. Susan Sosnowski, Dennis Algiere, Thomas Izzo, Donna Walsh, and Patrick McDonald introduced S2703 on February 7, 2002, and Representative Rabideau and Ginaitt introduced H7996 on April 04, 2002.

On November 6, 2001, Governor Almond declared the formation of the Governor's Commission on Lyme by executive order (Appendix A), and on January 29, 2002, he appointed the following individuals to the Commission:

- Joseph S. Larisa, Jr. Rhode Island Chief of Staff, as Chairperson
- The Honorable V. Susan Sosnowski. Member of the Rhode Island Senate who serves on the Education and Environmental Committees.
- The Honorable Peter T. Ginaitt. Member of the Rhode Island House of Representatives serving on the Health, Education, and Welfare Committees.
- Peter Brassard, M.D. Municipality representative and physician who has practiced in Woonsocket and Block Island and who has studied various tick-borne ailments
- Wendy Clough, M.D. Brown University Medical School faculty member and infectious disease specialist at Rhode Island Hospital
- Howard Ginsberg, Ph.D. Expert in epidemiology and public health working at the University of Rhode Island who has been researching tick control.
- Tobias Goodman, M.D. Municipality representative and practicing physician in Westerly.
- Dr. R. Scott Hanson, M.D. Expert in epidemiology and public health and member of the Washington County Medical Society
- Roger Lebrun, Ph.D. Entomologist at the University of Rhode Island who is currently studying the immune system of the Deer Tick.
- Thomas Mather, Ph.D. Microbiologist at the University of Rhode Island who is currently studying the *B. burgdorferi* bacterium.
- Patricia Nolan, M.D., MPH, Director of the Rhode Island Department of Health
- Jan Reitsma, Director of the Rhode Island Department of Environmental Management.
- Phil Rizzuto, M.D. Brown University Medical School faculty member and ophthalmologist.
- Lee Schisler. RI Audubon Society executive director.
- Debra Solomon, M.D. Practicing physician specializing in psychiatry and the neuropsychiatric aspects of Lyme disease.
- Michael M. Tikoian. Chairman of the Rhode Island Coastal Resources Management Council.
- J. Scott Toder, M.D. Practicing rheumatologist in Westerly
- Hazel Turley, BSN (Brown University), MBA (Bryant College) and Executive Committee Member of RI Chapter of Sierra Club.

The following are summaries of the meetings and hearings that took place under the Commission.

Governor's Commission on Lyme Disease and Other Tick-Borne Infections: First Meeting February 12, 2002

The first meeting of the Governor's Commission on Lyme Disease and Other Tick-Borne Infections was called to order at 7 p.m. in Conference Room B at the Department of Administration.

Present: Joseph S. Larisa, Jr, Chair; Utpala Bandy, M.D., Rhode Island DOH Epidemiologist; Peter Brassard, M.D.; Wendy Clough, M.D.; Howard Ginsberg, Ph.D.; Tobias Goodman, M.D.; Malcolm Grant of the RI Department of Environmental Management; Thomas Mather, Ph.D.; Philip R. Rizzuto, M.D.; Lee Schisler; Debra J. Solomon, M.D.; Senator Susan Sosnowski; Linda Tetu-Mouradjian, RN; Mike Tikoian; J. Scott Toder, M.D.; Hazel B. Turley, BSN, MBA; Darryl Paquette, President of Newport's Friends of the Waterfront; Peter Quattromani.

Absent: R. Scott Hanson, M.D.

Introduction

The meeting was called to order and chaired by Mr. Larisa. The meeting opened with introductions of all participants.

Agenda

Mr. Larisa announced that the Commission would be divided into two groups for future meetings: the Prevention and Environmental Issues Subcommittee and the Diagnosis and Treatment Subcommittee. All members received a copy of S 2703, introduced by Senators Sosnowski, Algiere, Izzo, Walsh, and McDonald. Mr. Larisa also announced that one function of the Commission would be to listen to testimony from the public and, ultimately, to make recommendations to counter the Lyme problem. The Commission members then proceeded to discuss many of the key issues regarding Lyme in Rhode Island including: the diagnosis of Lyme disease, the need to educate the public about ticks and Lyme, the need to educate physicians about Lyme, ways to prevent Lyme, the Lyme vaccine, the disparity between scientific literature and patient experience, and Connecticut policies on Lyme.

Meeting of the Subcommittees
March 6, 2002

Mr. Larisa called this meeting to order. He announced the manner in which the public hearings would progress, indicating that the Commission and Subcommittees would hear testimony from advocacy groups, physicians, and citizens affected by Lyme disease. The Commission then divided into the two subcommittees namely the Prevention and Environmental Issues Subcommittee, and the Diagnosis and Treatment Subcommittee.

Prevention Subcommittee

Present: Patricia Nolan, M.D., MPH, Chair; Linda Tetu-Mouradjian, RN, for Utpala Bandy M.D.; Malcolm Grant; Hazel Turley, BSN, MBA; Howard Ginsberg, Ph.D.; Roger Lebrun, Ph.D.; and Thomas Mather, Ph.D.

Introduction

Dr. Patricia Nolan, MD, MPH, called this meeting to order at 7:15 pm.

Issues

The subcommittee noted the insufficiency of prevention strategies employed by the general public. This, they said, was indicative of the public's lack of awareness as to the potential severity of tick bites and Lyme. Since such concern has not taken root among the general populace, there has been little demand for tick prevention strategies, meaning that businesses, homeowners, and institutions have not had the impetus to learn about and employ such strategies.

The subcommittee discussed missed opportunities to educate the public about tick prevention. There are problems in utilizing such activities and in employing prevention strategies on a wide scale; government is constrained by limited authority over the public domain and has a limited budget; and Lyme advocacy groups are greatly focused on the diagnosis and treatment of sufferers of tick-borne diseases, and are less active in education and prevention.

Recommended Strategies

The subcommittee discussed the role that government could play in the prevention of Lyme disease and in the education of its citizenry concerning Lyme disease. Suggestions included requiring cities and towns to regularly audit the habitat and to determine what areas have significant rates of infected ticks. Towns would also be encouraged to develop strategies to limit human exposure to ticks on public lands. To this end, the subcommittee would like to see each city and town designate a tick coordinator, who would advise the city on such strategies. State environmental agencies should be involved in tick auditing and control strategies. Employees working at outdoor recreational facilities should be educated in tick prevention and should employ such strategies to educate visitors about the hazards of tick-borne diseases and personal tick prevention. In terms of private property prevention strategies, this subcommittee recommended that landscapers could be educated to create tick-reducing designs that would also serve to reduce the presence of tick hosts such as deer and white-footed mice. The subcommittee would like to encourage the use of such strategies.

The subcommittee recommended that schools, day care centers, camps, and other child-centered programs disseminate information to both children and parents about personal protection, and encourage professionals to lead tick checks after exposure to potentially tick-infested areas. The subcommittee also recommended that physicians be involved in tick prevention education, not only by reporting tick-borne diseases, but also by providing appropriate educational materials based on a patient's age, occupation, and recreational activities.

Diagnosis and Treatment Subcommittee

Present: Joe Larisa, Chair, Peter Brassard, M.D.; Wendy Clough, M.D.; Debra Solomon, M.D.; J. Scott Toder, M.D.; R. Scott Hanson, M.D.; Senator V. Susan Sosnowski.

Meeting

This subcommittee discussed laboratory testing problems, issues in diagnosing Lyme disease, and issues in treating acute and chronic Lyme disease. No minutes are available.

Public Hearings

Public Hearing 1
April 8, 2002

Joseph S. Larisa Jr. opened the first public hearing at 6:00 pm in the Crowne Plaza at the Crossing in Warwick.

Testifying: Pat Smith, President of the Lyme Disease Association; Lyme Community Coalition of Rhode Island; Brian Fallon, M.D., Director of the Lyme Disease Research at Columbia University; Members of the General Public.

Expert Testimony

Ms. Smith spoke to the problem of insurance companies refusing a diagnosis of Lyme disease. Insurance companies claimed that patients diagnosed with Lyme disease do not fit the Centers for Disease Control definition of Lyme disease. She also testified that some physicians feared they could lose their licenses for treating Lyme disease, especially chronic Lyme disease. Ms. Smith said that the current lack of education about Lyme disease and the ineffectiveness of current Lyme disease tests have resulted in many infected individuals going undiagnosed and eventually developing chronic Lyme. She believed, she said, that chronic Lyme disease is more common than is reported, but physicians are coerced into not diagnosing or treating the disease. She wished to see a large-scale initiative in the Northeast to educate the public about acute and chronic Lyme disease and more money given for Lyme research. She would, ultimately, like to see more accurate tests for Lyme disease.

Dr. Fallon also testified that current Lyme disease tests are often inaccurate. He believed that the vast majority of Lyme patients who are treated early in the progression of the disease make a full recovery. However, in the absence of an accurate test combined with physicians who do not know how to make a proper clinical diagnosis, there are many patients who are not diagnosed until they reach the chronic stage of the disease. Dr. Fallon also testified that cognitive symptoms of the disease, which are often found in children, are often absent in the American medical literature and ignored by physicians. As to treatment, Dr. Fallon explained that some of the medical literature indicates that acute Lyme disease is easily treated with a four-week cycle of antibiotics, while other information in the literature claims that more aggressive treatment is needed. Dr. Fallon testified that the appropriate treatment of Lyme disease is still in question, and co-infections with other diseases, such as Babesiosis or Ehrlichia, may hinder typical Lyme disease treatment.

Public Testimony

Dozens of individuals spoke before the Commission, and dozens more submitted written accounts about their experiences with Lyme disease. Most accounts told tales fraught with misdiagnoses, disintegrating health, and battles with physicians and insurers. Nearly every individual who testified stated that their primary physician never diagnosed them with Lyme, or only diagnosed them after years of misdiagnoses, even if they presented with classic symptoms such as the *Erythema Migrans* rash. Sometimes, patients would request a Lyme test and be refused; others would present with many of the symptoms of Lyme but would not have a sufficiently conclusive ELISA test to be diagnosed with Lyme disease. In the latter cases, these individuals would be diagnosed with Multiple Sclerosis, Fibromyalgia, ALS, Lupus, Chronic Fatigue Syndrome, or one of a whole host of similarly symptomatic conditions. Many patients received no diagnosis at all. Some instead, were referred to psychiatrists for Munchausen Syndrome, Munchausen Syndrome by proxy, and other psychological disorders. Some sufferers, when they suggested the possibility of having "chronic" or "late term" Lyme, were diagnosed only after years of personal research and fighting with their primary physician or after finding a "Lyme-literate" physician.

Even if patients were diagnosed with Lyme, they reported that receiving treatment is a great challenge. While current mainstream Lyme literature maintains that Lyme is always cured by a four-week cycle of oral antibiotics, there were many who only responded to more powerful intravenous antibiotics, or only responded after lengthy treatment. Others reported having relapses whenever treatment was withdrawn. These patients often would not be able to receive treatment or else would not receive coverage for treatment beyond the four-week oral cycle. A few patients claimed that their physicians confided that, while they would like to prescribe an unorthodox treatment, they could lose their license when they filed a report with the insurance company, as many insurers consider such treatment to be "medically unnecessary," and therefore inappropriate or even detrimental. Several citizens reported that their physicians seemed intimidated by insurance companies, essentially pressured into not treating Lyme and chronic Lyme. Blue Cross/Blue Shield of Rhode Island was among those insurance companies hesitant to accept a diagnosis of Lyme disease in some cases. As a result, many individuals and families have been forced to seek out certain physicians to receive treatment, and have been plunged into financial crisis in order to pay for it.

A handful of those testifying reported that they or a loved one suffered from one of the other, less common tick-borne diseases. Many of these people were simultaneously infected with one or more of the tick-borne disease and Lyme, and while they might have shown the classic symptoms of Lyme and been appropriately treated for Lyme, the other diseases persisted after the eradication of the Lyme. Some who still seemed ill after treatment were aggressively treated for chronic Lyme, but to no avail. These individuals

had difficulty receiving an appropriate diagnosis and, hence, appropriate treatment for their diseases due to physician ignorance of these other diseases.

Almost all of those testifying shared the same concerns. They wish to see greater physician education with regards to the symptoms and treatment of Lyme and other tick-borne diseases. This education, they say, should include literature on chronic and late term Lyme and the persistence of Lyme after typical treatment. They expressed a need to receive a much greater degree of insurance coverage for their treatment. They wish to see the protection of physicians who, they believe, are appropriately treating Lyme.

Public Hearing 2
April 17, 2002

Joseph S. Larisa Jr. opened the second public hearing at 6:00 pm at the University of Rhode Island's Independence Square II Auditorium in Kingston.

Testifying: Karen Vanderhoof-Forschner, President of the Lyme Disease Foundation in Hartford, CT; David Nelson, Ph.D., a molecular biologist at URI; Leslie Fein, M.D., a rheumatologist from New Jersey; Steven Phillips, M.D., an internist from Connecticut; Sam Donta, M.D., Chief of Infectious Disease at the Boston University Medical Center; Anthony Lionetti, M.D., an internist from New Jersey; Amiram Katz, M.D., Neurologist from Yale University; Kenneth Liegner, M.D., an internal medicine and critical care specialist from New York; Charles Ray Jones, M.D., a pediatrician from Connecticut; Nick Harris, Ph.D., Immunologist and director at Igenex Labs in California; Joseph Burrascano, M.D., an internist from New York; Robert Bransfield, M.D.*, a psychiatrist from New Jersey; Members of the General Public.

Expert Testimony

In an attempt to receive diverse reports on Lyme disease, the Commission asked for reports from those on the "conventional" side of Lyme, who claim that the disease is easy to identify and treat, as well as reports from "alternative" believers in late term and chronic Lyme. However, all of the conventional specialists declined to attend. None of the testifying physicians practice in Rhode Island.

These experts echoed many of the concerns of Lyme sufferers. They testified that Lyme is a "persistent, recurring infection" which sometimes requires treatment far beyond the standard four-week oral antibiotic cycle. They also pointed to the lack of Lyme knowledge among many physicians, especially when it concerns patients without classic symptoms (according to the CDC, 20% of Lyme sufferers never develop the EM rash, which most physicians use to indicate Lyme) and those with chronic Lyme. And, similar

to the Lyme patients, the experts noted the problem of insufficient insurance coverage, blaming it on the dominance of conventional Lyme literature in medicine.

These experts explained the difficulty in studying and testing for Lyme in the human body. The bacterium that causes Lyme disease, *B. burgdorferi,* is difficult to culture from human tissue. Therefore, the analysis for Lyme disease relies on the detected presence of Lyme antibodies in the blood. Those testifying claimed, however, that someone who is immunocompromised might be very sick with Lyme, but would produce few, if any, antibodies against the disease. They also critiqued the quality and consistency of lab testing, advocating a more clinical than laboratory approach to diagnosis. Several experts also recommended that the CDC include neuropsychiatric symptoms in the guidelines for clinical diagnosis of Lyme disease.

A few experts testified as to the nature of the bacterium itself. They described a dormant form of the bacterium that is able to hide within human cells, limiting the extent to which it can be detected and eradicated by antibiotics. This property enables the bacterium to cause chronic Lyme, for which, these experts say, there is no cure, but may be adequately treated through the aggressive use of intravenous antibiotics.

These specialists asked the Commission to consider several suggestions. First, they wished to see the acknowledgement of chronic Lyme by the mainstream medical community and the education of physicians with regards to chronic Lyme and its possible treatment. They also wish to give the physicians more power in determining what treatments are medically warranted, allowing physicians to tailor treatments to their patients' individual needs. Also, insurance companies ought to be held responsible for covering more extensive treatment, as most treat the government-mandated minimums (such as those outlined in the original version of S2703) as the most they will pay for Lyme treatment. Lastly, they agreed that more research is required to find better treatments, and maybe even a cure, for chronic Lyme.

* Robert Bransfield, M.D., a psychiatrist from New Jersey, submitted extensive written testimony but was not present.

Public Testimony

The public testimony received at this hearing was similar to the testimony received on April 8.

Update on RI Laws Addressing Lyme Disease

In February of 2002, Senators Sosnowski, Algiere, Izzo, Walsh and McDonald introduced bill S2703 "An Act Relating to Lyme Disease Treatment." After amending the bill, it passed both chambers of the General Assembly and became effective on July 1, 2002. A new chapter, 5-37.5, entitled, "Lyme Disease Diagnosis and Treatment," was added to the Rhode Island General Laws. In the preamble, this chapter explicitly identifies chronic Lyme as a viable medical condition whose sufferers have difficulty obtaining both a correct diagnosis and appropriate treatment. It also notes that physicians who use long-term antibiotics on chronic Lyme patients have met with success, while many physicians who wish to treat Lyme feel threatened by insurers, as well as the lack of consensus in testing, diagnosis, and treatment. The bill ensures a greater degree of physician discretion in treating Lyme. Physicians may prescribe antibiotics for therapeutic treatment as long as they document the diagnosis and treatment plan, and do not dispense treatment that the medical licensure board deems inappropriate. However, the bill did not ensure health insurance coverage of cost for prescribed treatments.

A bill addressing Lyme disease and treatment, (2003 H 6136 Substitute A), was enacted into law on 07/03/03. Entitled "An Act Relating to Health and Safety--Lyme Disease Diagnosis and Treatment," this act requires health insurers to cover diagnostic testing and long-term antibiotic treatment for Lyme when prescribed by a licensed physician, regardless of whether the treatment is considered *investigational* or *unproven*. However, the requirements of this act will expire on December 31, 2004. Representatives Gallison, Anguilla, Enos, Lewiss, and Amaral introduced the original version of this bill to the House Floor on February 27, 2003. Senators Damiani, Pollisena, and Sosnowski introduced S 1173, a companion bill, to the Senate floor on June 26, 2003.

Recommendations of the Commission

The following is a summary list of the recommendations that were reviewed by the Commission:

- Educate the public about Lyme disease including: recognizing ticks, the hazards of ticks, how to prevent tick bites, strategies for preventing Lyme disease, and symptoms of Lyme disease.
- Educate the public through physicians' offices, emergency rooms, clinics, schools, and childcare centers.
- Educate the public about Chronic Lyme disease.
- Educate physicians about Lyme disease, including such topics as understanding all the criteria that can be applied to diagnose Lyme disease, how to recognize all the possible symptoms and deviations from the common symptoms, and knowledge of the scope of potential treatments and their side effects.
- Educate physicians about Chronic Lyme disease.
- Investigate the possibility of having a Tick Coordinator for the State of RI.
- Survey the tick population throughout the entire state.
- Examine tick-reducing landscaping techniques.
- Examine the use of pesticides as they relate to Lyme disease.
- Ensure occupational protection for high-risk State employees.
- Investigate strategies for deer control.
- Allow physician discretion in clinical diagnosis of Lyme disease. Allow diagnosis to be wider than outlined in the CDC guidelines.
- Allow physician discretion in treatment of Lyme disease, including the prescription of long-term antibiotics.
- Recognize Chronic Lyme disease as a problem in Rhode Island.
- Require insurers to extend coverage on Lyme treatment.
- Protect physicians who diagnose chronic Lyme disease from censure by medical review boards and insurers.

APPENDIX A

State of Rhode Island and Providence Plantations
State House
Providence, Rhode Island 02903-1196
401-222.2080

LINCOLN ALMOND
GOVERNOR

EXECUTIVE ORDER
01-09
November 6, 2001

GOVERNOR'S COMMISSION ON LYME DISEASE AND OTHER TICK-BORNE INFECTIONS

WHEREAS, the Department of Health has collected disease reports on the incidence of Lyme disease in Rhode Island since 1982, and has had a case surveillance system for Lyme disease from 1991 to 2000; and

WHEREAS, the University of Rhode Island has developed and maintains a statewide vector surveillance system that provides data on the density of the tick population in the state. The data shows a strong correlation between the incidence of disease and the abundance of ticks; and

WHEREAS, this surveillance demonstrates that Rhode Islanders have a disproportionately high rate of Lyme disease compared to residents of most other states, with the highest rates of Lyme disease occurring in Washington County; and

WHEREAS, this surveillance also demonstrates a trend toward an increased incidence of other, rarer tick-borne infections; and

WHEREAS, the Rhode Island departments of Health and Environmental Management and the University of Rhode Island have an active public information campaign intended to prevent Lyme disease and other tick-borne infections; and

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November 6, 2001
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WHEREAS, the Department of Environmental Management has responsibility for managing state lands, including state parks, where control of tick populations and prevention of Lyme disease is important for both staff and visitors; and

WHEREAS, the diagnosis of Lyme disease may be delayed or missed, leading to prolonged illness, and the treatment of prolonged illness with Lyme disease remains somewhat controversial, creating substantial public concern among the citizens of Rhode Island; and

WHEREAS, given current limitations on the diagnosis and treatment of Lyme disease, prevention is the most effective weapon in fighting infection; and

WHEREAS, the prevention of Lyme disease and other tick-borne diseases is best accomplished by a combination of medical, personal protection, and environmental management intervention.

NOW THEREFORE, I LINCOLN C. ALMOND, by virtue of the power vested in me as Governor of the State of Rhode Island and Providence Plantations, order as follows:

1. There is hereby established a Governor's Commission on Lyme Disease and Other Tick-Borne Infections.

2. The Commission shall examine data on Lyme disease and other tick-borne infections that lead to human disease, hold hearings and receive testimony from medical, public health and environmental experts, along with members of the public.

3. The Commission shall consist of eighteen (18) members appointed by the Governor as follows: the Governor's Chief of Staff who shall serve as Chairperson of the Commission; the Director of the Department of Health; the Director of the

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November 6, 2001

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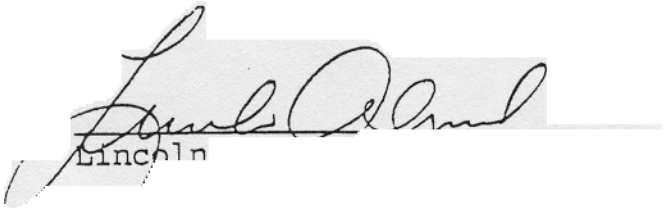
Department of Environmental Management; a representative of the Coastal Resources Management Council; two (2) representatives of environmental advocacy groups; two (2) representatives of municipal government who by virtue of occupation or specialized training have an interest in the control of tick-borne diseases; two (2) members of the faculty of the University of Rhode Island with environmental tick control expertise; two (2) practicing physicians with interest and expertise in treating Lyme disease; two (2) medical school~ faculty with expertise in infectious disease; two (2) persons with expertise in epidemiology and public health; one (1) member of the House of Representatives and; one (1) member of the Senate.

4. The Commission may form such subcommittees as it deems appropriate.

5. The Commission shall make its written recommendations to the Governor and the General Assembly by March 1, 2002.

This Executive Order shall take effect immediately upon the date hereof.

So Ordered:



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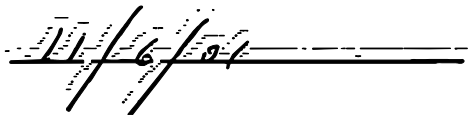

Appendix B:

Tick-Borne Disease in Westerly: Special Meeting August 31, 2000

A meeting of the Taskforce on Tick-Borne diseases in Westerly was called to order at 12:00 pm in the Nardone Community Room pursuant to the notice sent to all interested participants.

Participants:
Mr. Boll, a member of the community
Erica E Jost, M.D.
Russell N Bingham, M.D.
Allen W. Leadbetter, M.D., practicing surgeon at the Westerly Medical Center
Allen Gettman, Ph.D., Mosquito specialist for the Rhode Island Department of Environmental Management.
Patricia Nolan, M.D., MPH, Director of the Rhode Island Department of Health
Mr. Fusaro
Mr. Donnelly
Senator Dennis L. Algiere, representing the Town of Westerly
Representative Peter L. Lewiss, representing the Town of Westerly
Representative John J. Thompson, member of the Rhode Island House Committee on Health, Education, and Welfare
Warren Woodworth, M.D.
Mr. Lally
Thomas Mather, Ph.D., researcher on ticks and tick-borne diseases at the University of Rhode Island
Diane Selvidio, RN
Carol May, manager of the laboratory at Westerly Hospital
Walter Pannone, RN, a nurse at Westerly Hospital
Tobias Goodman, M.D., a practicing physician in Westerly

Problem of Tick-Borne Disease in Westerly

Westerly health officials reported that 5% of all patients seen in the emergency room were found to have some tick-borne disease and also reported that the town had seen a great degree of disability among the professional staff as a result of these ailments. The cost of testing these patients for Lyme is great, at $56 a test, totaling $140,000 in Westerly alone in 1999. Of course, when we take into account the cost of lost wages, prescriptions, and physician visits, the cost of tick-borne diseases is even higher.

Possible Strategies

The meeting worked to identify problems that the town and the state could address. Dr. Patricia Nolan, MD, MPH, Director of the Rhode Island Department of Health, noted that a major issue was the public lack of awareness of the severity of Lyme. Individuals need to be aware, she said, of just how damaging Lyme can be to their health so that they will take more active precautions to avoid tick bites. Another suggestion came from Rhode Island state mosquito specialist Alan Gettman, Ph.D. who brought up the possibility of having state and local tick specialists who would survey and study the tick population and the presence of bacteria in the tick population. Thomas Mather, Ph.D., a microbiologist at the University of Rhode Island specializing in Lyme, concurred that tick and disease surveillance is important in helping to determine why the rate of reported infection has increased over the years.

Appendix C:

Connecticut Lyme Policy

Information is absent on whether the Commission ever actively discussed Connecticut Lyme policy. However, there is some information available from the Connecticut Agriculture Experiment Station (CAES) website (http://www.caes.state.ct.us/) on how Connecticut has tackled the Lyme problem. Kirby Stafford III, Chief Scientist at CAES, whom the Prevention Subcommittee considered consulting, has reported on some of the experiments he has conducted to reduce human contact with ticks in Connecticut. In 1998, he reported that the use of habitat-reducing landscaping techniques (such as removing leaf debris from one's yard) and the application of combinations of certain pesticides could greatly reduce the tick population in an area. The CAES was also interested in directly addressing the deer tick's primary host, the white-tailed deer. Using an electric deer fence to exclude deer from an area led to the elimination of larval ticks in the area and the reduction (by 84% and 74%, respectively) of nymphal and adult ticks. At the time of the report, Stafford was experimenting with treating deer with livestock-friendly pesticides, estimating that it would lead to a 90% reduction in the tick population within four years. The State of Connecticut also works with the University of Connecticut to educate schools as to the hazards of Lyme and how to avoid tick bites.

In the years preceding the Commission, the Connecticut General Assembly drafted a handful of bills to address the Lyme issue. In 1999, the Health Committee unanimously approved an act requiring insurers to cover extended Lyme disease treatment when prescribed by a board-certified rheumatologist, infectious disease specialist, or neurologist. The contents of the bill were placed in a general public health

bill. HB7501, "An Act Concerning Expenditures for Programs and Services of the Department of Public Health," passed the General Assembly and was signed into law. As of 2000, the Connecticut Statutes Chapter 700c Sec38a-492h orders mandatory coverage of 30 days of IV antibiotics and 60 days of oral antibiotics for Lyme treatment. Additionally, insurers must cover further treatment if required by a board-certified rheumatologist, infectious disease specialist, or neurologist. Another 1999 bill to legalize controlled deer hunting, partially to counter the Lyme disease problem, never left the Environmental Committee. Two 2001 bills, one to create a "Task Force" to study Lyme, and another to form a "Lyme Awareness Council" never made it out of the Health Committee.

Appendix D:

Federal Lyme Law

In 2001 and 2002, several senators and representatives from states with high tick-borne disease infection rates (including Connecticut, Pennsylvania, New York, New Jersey, Massachusetts, Oregon, and Ohio) sponsored a handful of legislation aimed at alleviating the tick-borne disease problem. S 969, "An Act to Establish a Tick-Borne Disease Advisory Committee," was sponsored by Senator Christopher Dodd and passed the Senate unanimously, but, after being referred to the House Subcommittee on Health, never made it to the House floor. An earlier House version of S 969, HR 2118, entitled the "Lyme and Infectious Disease Information and Treatment (LIIFT) Act," also never made it out of the House Subcommittee on Health. Another bill, HR 1254, "The Lyme Disease Initiative of 2001," which would have focused more national health research and funds on tick-borne disease, suffered a similar fate. On July 31st, 2003, Senators Rick Santorum and Christopher Dodd reintroduced the "Act to Establish a Tick-Borne Advisory Committee" as S 1527, citing the need to aid persons infected with Lyme disease and prevent further infection.

Appendix E:

Blue Cross/Blue Shield Policy

In August 2002, Blue Cross/Blue Shield of Rhode Island (BCBSRI) made an agreement with the Governor's Office to cover long-term treatment rather than deny it simply because it is investigational. However, in January 2003, the Department of Health found that BCBSRI was continuing to deny long-term antibiotic treatment. The agreement was voided.

BCBSRI proposed to revise its Lyme treatment coverage policy. On April 15, 2003, two BCBSRI representatives (Augustine Manocchia, M.D., BCBSRI Medical Director, and Peter Hollmann, M.D., BCBSRI Senior Medical Director) met with four physicians (Sam Donta, M.D., Commission member Wendy Clough, M.D., James Gloor, M.D., and Harry Schrager, M.D.) to discuss the value of intravenous antibiotic treatment of chronic Lyme disease to more appropriately update their policy in accordance with the Utilization Review Law.

All four physicians testified to their varying uses of IV antibiotics. Although they acknowledge that medical literature still considers the use of these antibiotics in the treatment of Lyme to be investigational, the physicians expressed their belief that IV antibiotics are needed in cases where oral antibiotic treatment has failed. BCBSRI is still in the process of reviewing and revising its Lyme policy, but fiercely opposes the Lyme bills. Dr. Manocchia, M.D. has stated that he does not believe that BCBSRI members should pay for treatment that has not been "proven," according to the scientific literature, to be effective.

HEALTH
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Appendix F: Copy of DEM Memo

DEPARTMENT OF ENVIRONMENTAL MANAGEMENT

INTER-OFFICE MEMORANDUM

DATE: **September 8, 2003**

TO: **Dr. Patricia A Nolan, MD,MPH**

FROM: **Jan H. Reitsma**

SUBJECT: **Governor's Commission on Lyme and other Tick-borne Diseases**

Dear Pat,

Mal Grant and Al Gettman reviewed the Tick-borne Disease Commission Report per your request and both support the creation of a position in Al's office to:

1. Conduct public awareness campaigns
2. Conduct applied field research
3. Reduce human exposure on state recreation lands through physical means (cutting and cleaning) and chemical means (pesticide application)
4. Assist communities to similarly reduce risks on their public lands.

The report is overall a complete and accurate summary of the Commisssion's work.

e-mail response

Appendix G: Table of Recommendations Reviewed by the Commission

	Education	Tick Control	Diagnosis	Treatment	Chronic Lyme	Insurance
P/E Subcommittee	Education of Physicians, public through phys., schools, child care workers, parents	Have tick coordinator, survey tick population, landscaping, pesticides occupational protection, look into deer control				
D/T Subcommittee						
Public	Education of public about ticks and Lyme dangers, phys. about symptoms, treatment, & chronic Lyme		Lyme literate physicians should dx; looser than CDC guidelines	Treatment at discretion of Lyme literate physicians, including long term antibiotics	Chronic Lyme exists and must be recognized	Insurers must extend coverage on Lyme treatment, must not bully physicians
Expert	Education of physicians about all ways to diagnose, potential treatments, & chronic Lyme		Clinical dx left to physicians; CDC guidelines plus neuroencephalopathy	Treatment at discretion of physicians, including long term antibiotics	Chronic Lyme exists and must be recognized	Insurers must extend coverage on Lyme treatment, must not bully physicians
Insurer				Holds with mainstream Lyme literature; at time cover 4-week oral antibiotic cycle only	Holds with mainstream Lyme literature; at time did not acknowledge chronic Lyme	Will cover only what is "medically indicated"
CT Policy	Attempted to form Lyme Awareness Council; collaborates w/UConn to educate schools	Examine landscaping, pesticides, deer control; has people studying tick control		Treatment largely at discretion of certified rheumatologist, infectious disease specialist, or neurologist	Acknowledges existence of persistent Lyme	Law states long term treatment must be covered if ordered by certified rheumatologist, infectious disease specialist, or neurologist